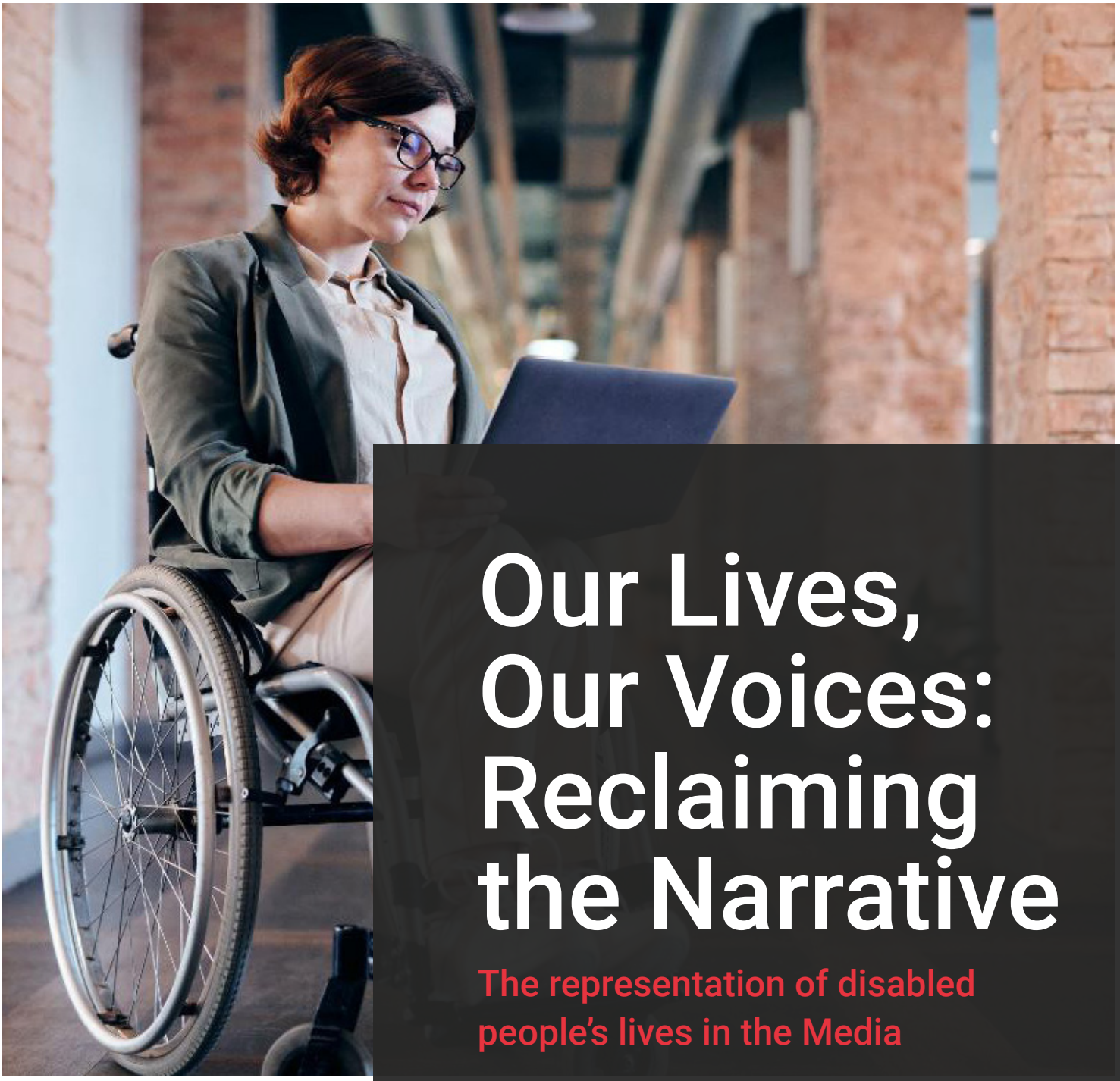

Our Lives, Our Voices: Reclaiming the Narrative

The representation of disabled people's lives in the Media

ILMI Position Paper February 2022

ILMI
INDEPENDENT LIVING MOVEMENT IRELAND

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Our Lives, Our Voices

Introduction from Des Kenny, ILMI Chairperson

> On our rare appearances on media, we are invited to speak solely on our personal lives: the lack of services, the barriers to our participation.

In the year that Ireland makes its first report to the United Nations under the Convention of Rights of Persons with Disabilities (UNCRPD) there a number of issues relating to the full and active participation of disabled people in Irish society as equals.

One aspect of social life has a huge impact on the framing of our lives, yet it shows the greatest resistance to change: the Irish media. We as disabled people can expect any number of stories about our lives in print, broadcast and online media. The stories are always the same: the tragedy of the disabled person or the inspirational disabled person who has overcome their impairment. We are continually reduced to either tropes. We are exploited for charitable purposes.

On our rare appearances on media, we are invited to speak solely on our personal lives: the lack of services, the barriers to our participation. Despite these tropes, we as disabled people and our lives are not defined by our impairments. We live full and active lives. By focussing on our impairments, Irish media perpetuates a medical / charity approach to disability.

We need commitment from media companies, policy makers and trade unions to co-create with disabled people pathways to inclusion. We need a commitment to working with us through our representative DPOs to hear how media can harness the talents and skills of disabled people. Working with us can move from a medical / charity narrative towards a fuller social model analysis of disability. We can work in partnership to move away from offensive language or patronising stories of “care” or “vulnerability” and focus on ensuring disabled people are active in creating media: as journalists, artists, actors, presenters and producers.

Media in Ireland in the 21st Century needs to reflect the diversity of our Island in how media is created, presented and written. We need to think about the intersection of those identities and ensure we start to not only have disabled journalists, producers and presenters but also ensuring the full and active participation of Travellers, minority ethnic groups, LGBTIA people, asylum seekers, lone parents and people who experience marginalisation due to socioeconomic status.

Media in Ireland needs to hear the rallying cry of the global Disability Rights Movement: “Nothing About Us Without Us”. That is the least of our demands for the creation of media around our lives as disabled people in the 21st Century.

Des Kenny
Chairperson

Disabled People and the Irish Media

The media plays a crucial role in shaping discussions in relation to disability. On Tuesday 1st December 2020, ILMI hosted an online discussion with disabled activists to collectively look at how disability is discussed, narratives that are used and the impact of stories and language used that impacts our lives as disabled people.

ILMI created this space for disabled people in order to develop a strong collective voice representing disabled people to shape the narrative of how media engages with disability and disabled people.

"Our Lives, Our Voices" is based on the facilitated discussions disabled activists held and their thoughts on how disabled people are currently represented, how we as disabled people would like to be represented and changes that are needed in the development and production of media in Ireland.

1. How do disabled people feel they are represented in Irish media?

We as disabled people are often missing from Irish media, in everyday discussions, dramas and productions. Where disabled people are represented in media (broadcast and print) it is often quite patronising to us. Media only seem to be interested in a "sob story" because we are disabled.

The main narrative is either one of "tragedy" of our impairments or the "inspirational" disabled person who has "overcome" our impairment. Disability is seen through the aforementioned "medical model" in the Irish media as a charity issue and the narrative is often "poor them". Disabled people are often only sought out to give our "personal stories" and not about how society disables us and prevents our full and active participation in society.

A significant representation of disabled people is that our voices are not heard, but that discussions around disabled people is through the voices of parents or "carers". Disabled People's lives are discussed in terms of how the family "copes" with us and the "burden of care". There is no regard given to how we as disabled people feel in having our lives on national print or broadcast media being discussed by our families as being a "burden". There is no discussion about how we feel about having to rely on family members for support and how that impacts on our choice and control over our lives. Again, this is the "tragedy of disability" narrative predominating in Ireland.

There are a small number of disabled people who have a platform – but that isn't often positive, as it is framed in terms of "inspirational" disabled people who have "overcome" their impairment.

As Disabled people we rarely see ourselves in media accurately and this will only change when we as disabled people are directly involved in the production of media: as presenters, writers, actors, audience members.

"There are a small number of disabled people who have a platform - but that isn't often positive, as it is framed in terms of "inspirational" disabled people who have "overcome" their impairment."

2. How disabled people would like to be represented in the Irish media

Disabled people want to see ourselves fully represented in Irish media. We share the same issues as everyone else, and want to be seen as part of society, with the same range of interests, passions and emotions and the fullness of human experience, the same as non-disabled people: mothers, fathers, brothers, sisters, work colleagues, employers, and so on.

Disabled people should be presented just as doing normal things and living our normal lives. Disabled people should not be defined by their impairment, this has to change. Being disabled is not a tragedy and we do not want or need “pity”. We need to engage and employ disabled people to ensure we avoid continually portraying these offensive tropes. As disabled people we live with our impairments and we are not defined by them- and the media needs to have disabled people framing the narrative to move away from “tragedy” or “inspiration”.

Disabled people need to be visible in Irish media: as presenters, producers and panel members in discussions. Disabled actors need to be employed to act in dramas, and especially when disability is part of the story. There is a whole world of disabled art, dance, theatre, yet none of this is seen or reported on. Irish media only covers disabled people in a “pitiful way”, this has to change!

3. What do disabled people want to see from Media Companies in Ireland?

Media Companies, the Trade Union Movement, Government Departments and the Broadcasting Authority of Ireland need to explore how to reflect diversity in the production, delivery and presentation of media in Ireland.

That discussion needs to plan, resource and implement real inclusion in media for disabled people in the 21st Century. This can be done by directly consulting and engaging with us as disabled people who have the real lived experience of disability and by engaging with Disabled Persons Organisations (DPOs) who are led by and for disabled people.

Disability needs to be framed in discussions around inclusion, human rights and equality. Where there are discussions on issues that impact on society (access to education, employment, housing and homelessness, transport, social inclusion, religion, arts, culture, gender, politics and so on), we as disabled people should be involved. There is an intersection between disability and other issues that consistently remains unexplored in Irish media due to the consistent framing of disability as a medical / charity issue and by not exploring disability through the social model, which recognises the fullness of disabled people's lives and how disability intersects with gender, ethnicity, socioeconomic status, sexuality and so on.

The development of training, guidelines and frameworks of how journalists report on disability needs to be led by Disabled Persons Organisations (DPOs). The discussion on how to shape how the media talks about disability needs to be led by disabled people: "Nothing About Us Without Us". We need to move away from offensive tropes about disabled people "overcoming" or being "fixed". It is offensive and needs to stop.

"That discussion needs to plan, resource and implement real inclusion in media for disabled people in the 21st Century."

> Our vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals.

Introduction to Independent Living Movement Ireland

Independent Living Movement Ireland (ILMI) is a campaigning, national cross-impairment Disabled Person's Organisation (DPO) that promotes the philosophy of independent living and seeks to build an inclusive society.

Central to the way we work is to ensure that policy decisions that impact on the lives of disabled people must be directly influenced by those whose lives are directly affected. Our philosophy can be summed up as: 'Nothing about us without us!' and 'Rights Not Charity'. Our vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals.

Independent Living is about having the freedom to have the same choices that everyone else has in housing, transportation, education and employment. Independent Living is about choosing what aspects of social, economic and political life disabled people want to participate in. Independent Living is about having control over your life, to have a family, to get a job, to participate socially and to realise your goals and dreams.

What is the social model of disability?

The social model looks at how society is structured and how it disables people. It is not based on a person's impairment, it is focussed on the barriers that exist in terms of attitudes, policy development, access or lack of supports that prevent people from participating in society as equals, with choice and control over their own lives.

In this model it is society that disables people from achieving their hopes and dreams, not a person's impairment. The social model informs all aspects of the work of Independent Living Movement Ireland.

ILMI's work is to develop policies and campaigns based on disabled people's lived experiences in order to remove barriers that restrict life choices for disabled people. When barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives. Barriers are not just physical. Attitudes found in society, based on prejudice or stereotypes (also called disablism), also disable people from having equal opportunities to be part of society. Disabled people developed the social model of disability because the traditional medical model did not explain their personal experience of disability or help to develop more inclusive ways of living.

The social model of disability informs key International Conventions such as the UN Convention of the Rights of Persons with Disabilities (UNCRPD) and is in contrast to the "medical / charity model" of disability.

The **medical / charity model** individualises disability and promotes the idea that people are disabled by their impairments or differences. The medical model always focuses on people's impairments from a medical perspective. In some ways it still looks at what is 'wrong' with the person and not what the person needs. It creates low expectations and leads to people losing independence, choice and control in their own lives. The medical / charity model never recognises the rights of disabled people and assumes that disabled people need to be "looked after" or "cared for". Under the medical / charity model professionals make decisions for disabled people.

Language and representation of disabled people

Independent Living Movement Ireland recognises that language is a very powerful and evocative tool.

Therefore, the language and terminology used in this submission has been carefully chosen to reflect the values of equality and empowerment which is at the core of this organisation. The term ‘disabled people’ has been used throughout the submission in accordance with the UPIAS classification of disability and impairment which has been developed by disabled people themselves (UPIAS 1976). Where disabled people are referred to in the submission this should be understood to include all disabled people, including those with learning difficulties, issues relating to trauma and emotional distress and sensory impairments.

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Disabled People’s lives are discussed in terms of how the family “copes” with us and the “burden of care”. There is no regard is given to how we as disabled people feel in having our lives on national print or broadcast media being discussed by our families as being a “burden”. There is no discussion about how we feel about having to rely on family members for support and how that impacts on our choice and control over our lives. Again, this is the “tragedy of disability” narrative predominating in Ireland.

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